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Promoting exercise adherence among adults with knee osteoarthritis: a new look

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Boston University

BOSTON UNIVERSITY
SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

Dissertation

**PROMOTING EXERCISE ADHERENCE AMONG ADULTS
WITH KNEE OSTEOARTHRITIS: A NEW LOOK**

by

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requirements for the degree of
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"Trust in Him and do not fear. The peace of God will protect your hearts. Alleluia"

Fiez-vous en lui

The community of Taizé

DEDICATION

I would like to dedicate this work to Steve Ledingham as a small tribute to his huge contribution of love and moral support.

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PROMOTING EXERCISE ADHERENCE AMONG ADULTS

WITH KNEE OSTEOARTHRITIS: A NEW LOOK

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ABSTRACT

BACKGROUND: Exercise is an established treatment to alleviate pain and improve function among adults with knee osteoarthritis (KOA). However, long-term adherence to exercise is poor and effective approaches to support adherence are limited. The objective of this dissertation was to 'gain a new look' into long-term exercise adherence. With study #1, the experiences of participants in the Boston Overcoming Osteoarthritis through Strength Training (BOOST) study, were explored to identify participants' experiences, feelings and perspectives with exercise over 2-years and factors that influenced adherence to a prescribed exercise program after 2 years. With study #2, we examined if kinesiophobia: i) was associated with physical performance measures, ii) improved after a 6-week exercise program and iii) change was associated with change in pain and function among adults with KOA.

METHODS: Participants of both studies completed a 6-week exercise program. For study #1 all participants received an automated telephone reminder to continue with their exercises and complete their logs, in addition, those randomized into the intervention group received a motivational computer adaptive telephone program. Participants were purposively sampled and in-depth interviews were conducted at the 2-year assessment.

For study #2, data analysis was conducted prior to randomization with a sample of participants who completed the Tampa Scale of Kinesiophobia (TSK) questionnaire. Additional data included stair negotiation, 5 and 10 time sit-to-stand, and timed-up-and-go tests.

RESULTS: Study #1: Three themes were identified describing beliefs about exercise: i) monitoring, ii) knowledge of how to manage exercise behaviors, and iii) benefits of exercise. Those who reported high-adherence exhibited self-determination and self-efficacy, those who reported low-adherence expressed ambivalence about the benefits of exercise and a desire for more social support. Participants valued monitoring by peers and instructors during the exercise class and telephone technology. Study #2: Higher TSK was associated with slower stair and 5 time sit-to-stand times. TSK decreased after the exercise class but did not attain statistical significance. Change in TSK was associated with change in self-report physical function.

CONCLUSIONS: Future research on the use of telephone technology and importance of self-determination and kinesiophobia on exercise adherence among adults with KOA is warranted.

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LIST OF ABBREVIATIONS

| | |
|------------|------------------------------------------------------------|
| BOOST..... | Boston Overcoming Osteoarthritis through Strength Training |
| CI..... | Confidence Intervals |
| KOA..... | Knee Osteoarthritis |
| MCID..... | Minimal Clinically Important Difference |
| OARSI..... | Osteoarthritis Research Society International |
| RCT..... | Randomize Controlled Trial |
| SE..... | Standard Error |
| TLC..... | Telephone-linked communication |
| TSK..... | Tampa Scale of Kinesiophobia |
| TUG..... | Timed-Up-and-Go |
| WOMAC..... | Western Ontario McMaster Universities Osteoarthritis Index |

INTRODUCTION

Knee osteoarthritis, a complex chronic disease affecting 14 million adults in the United States,¹ is a leading cause of disability. The pathophysiology of knee osteoarthritis is insidious and multi-factorial, involving bone, synovial fluid, nerve, meniscus, ligaments and muscle.^{2,3} Risk factors include older age, obesity, female sex, history of physical trauma, type of occupation, and family history.^{2,4} Symptoms are characterized by pain, joint stiffness, crepitus, edema, muscle dysfunction, loss of joint mobility, and locking or buckling. Consequential outcomes include functional limitations: 30% of adults with knee osteoarthritis have difficulty rising from a chair, 45% have difficulty walking one-quarter mile, and 47% have difficulty negotiating 10 steps.⁵ One non-pharmacological widely recommended treatment to improve function and abate pain is exercise.⁶⁻⁹

Exercise is a planned structured intervention with the intention to improve health or maintain physical fitness.¹⁰ Recommended exercises for knee osteoarthritis include strength training, low-impact aerobic exercises, aquatic programs and flexibility exercises.¹¹ Strength training specifically addresses muscle function and should be performed twice weekly. However, less than 21% of adults (45–65 years) perform strength training as recommended by the *2008 Physical Activity Guidelines for Americans*.¹⁰ Adults with knee osteoarthritis exercise even less than age-matched peers.¹²

The success of exercise benefits is dependent on exercises being performed. Large proportions of adults with knee osteoarthritis who begin an exercise program cease exercising. In an 18 month randomized controlled trial, participants with knee

osteoarthritis performed exercises for three months in a class setting followed by 15 months of home-based exercises that included telephone support for exercise adherence.¹³ Upon completion of the exercise class 15% of participants were not adhering to the prescribed amount of exercise and by 18 months only 50% were adhering to the prescribed exercise program.

In a more recent study in which performance of home exercises after individual physical therapy treatments among patients with osteoarthritis of the hip or knee or both was examined, 43% were not adhering to the prescribed amount of exercise upon completion of the physical therapy treatments.¹⁴ At 15 months, the non-adherence rate was 66% of participants with an additional 4% decline in adherence at 60 months. In total 70% of participants were non-adherent to the home exercise program at five years.

Poor adherence to evidence-based exercise programs significantly reduces the benefits of exercise. Fostering long-term adherence to evidence-based exercise programs is well recognized as an essential area of needed research.¹⁵⁻¹⁷ Few evidence-based approaches exist. Furthermore, the majority of research pertains to exercise adherence for one year or less¹⁵, for adults with chronic knee osteoarthritis, years of adherence to exercise are necessary for life long enhancement of pain relief and functional improvements.

This dissertation work is designed to "take a new look" at exercise adherence. New strategies are clearly needed to promote long-term adherence to evidence-based exercise. To address this gap, two areas are examined: 1) perspectives of adults using automated telephone technology, over two years, to support individuals at

home subsequent to attending a group exercise program, and 2) the relationship of fear of movement —kinesiophobia— with function among adults with painful knee osteoarthritis.

Automated telephone technology, specifically computer adaptive systems, provide communication between patients and health professionals.¹⁸ The telephone-linked communications (TLC) system is an example of a computer adaptive automated telephone system that uses voice for communication and provides theory based counsel and motivation to promote behavior change. The efficacy of a TLC approach to promote more physical activity and better dietary choices among the general adult population is well established.^{19–21} However, the efficacy of this approach among adults with knee osteoarthritis is not known. The Boston Overcoming Osteoarthritis through Strength Training (BOOST) study used TLC technology to promote adherence to strength training exercises for two years after study participants attended a six-week exercise class at Boston University. Exercise adherence was the primary outcome. The first study of this dissertation is an ancillary study to the BOOST study designed to explore the study participants' perspectives of the BOOST study, and adherence to an evidence-based strength training exercise program over two years.

The second study of this dissertation explores the role kinesiophobia may have among adults with painful knee osteoarthritis. Kinesiophobia is a biopsychosocial concept related to fear of movement due to one's belief that movement will cause pain and physical harm.²² Among people with chronic back pain, kinesiophobia is associated with and predictive of functional limitations.²³ Furthermore, among people with chronic

back pain and high kinesiophobia, decreases in kinesiophobia was shown to improve physical function.²⁴ Several studies provide evidence to the benefits of exercise and cognitive interventions in ameliorating kinesiophobia, physical function and psychological dysfunction among people with chronic low back pain.²⁵⁻²⁷

Research on the role kinesiophobia plays with function and exercise among adults with knee osteoarthritis is limited. Cross-sectional studies show kinesiophobia is negatively associated with self-reported physical function^{28,29} and fast gait speed.³⁰ The relationship of kinesiophobia to other common performance-based functional assessments as well as whether kinesiophobia changes over time among adults with knee osteoarthritis is not known. In study two, the relationship of kinesiophobia with performance based measures of physical function and changes in kinesiophobia over a six-week exercise program were examined. This is an important initial step into gaining an understanding of the role kinesiophobia has in function and exercise among adults with knee osteoarthritis.

STUDY ONE

Exercise Adherence: Beliefs of Adults with Knee Osteoarthritis Over 2-Years

Exercise is an established treatment to alleviate pain and improve function in adults with chronic arthritis. Knee osteoarthritis, the most prevalent form of arthritis, affects 14 million adults,¹ is a leading cause of functional limitations among older adults in the United States.³¹ Functional limitation is common: 30% of adults with knee osteoarthritis have difficulty rising from a chair, 45% have difficulty walking one-quarter mile, and 47% have difficulty negotiating 10 steps.⁵ Osteoarthritis worsens muscle function through weakness, atrophy and neuromuscular inhibition.³²

Recommended exercises for knee osteoarthritis include strength training, low-impact aerobic exercises, aquatic programs, and flexibility exercises.¹¹ Strength training specifically addresses muscle function and should be performed twice weekly. However, less than 21% of adults (45–65 years) perform strength training as recommended by the *2008 Physical Activity Guidelines for Americans*,³³ with adults having knee osteoarthritis exercising even less than age-matched peers.¹² Furthermore, adults participating in clinical trials often cease exercising after the intervention is completed thereby abating the benefits of exercise.^{13,14,34,35} With the benefits of exercise clearly established, researchers are increasingly focusing on solutions to foster long-term adherence to exercise.

Internal and external motivational factors may have an effect on adherence to exercise among adults with knee osteoarthritis. Internal factors include a person's knowledge and understanding of osteoarthritis, beliefs in the benefit of exercise, self-

efficacy and self-determination regarding exercise, previous exercise experience, ability to continue with exercise despite comorbidities and unpleasant symptoms and finding time to exercise.^{16,36–39} External factors include support received from health professionals, friends, family, or any combination of these groups, as well as access to exercise facilities, transportation availability and weather.^{16,40}

Factors may differ between initial and long-term adherence.^{36,41} In a study examining adherence with a prescribed physical therapy home program, Campbell et al. showed initial adherence was influenced by a sense of obligation to the physical therapist, a desire to help researchers' quest for knowledge, a desire to avoid medications and by their positive regard for physical therapy. Whereas long-term adherence (i.e. 12 months) was influenced by pragmatic matters, for example, having time to exercise.

In a systematic review of 42 studies¹⁵ the authors concluded that supervised individually tailored exercise, with gradual progression of exercise difficulty fostered adherence. In addition, booster sessions, supplementary instructional materials, and education in self-management and behavioral principles also benefited adherence. However, few studies had adherence as the primary outcome and heterogeneity of intervention programs and outcome measures limits the ability to draw conclusive results.

While there is a clear benefit of exercise to manage knee osteoarthritis,^{6–9} evidence-based approaches to foster adherence to exercise are scarce and meaningful factors to support adherence to strength training exercise regimes remain elusive. The purpose of this study was to explore the experiences of participants of a large RCT, the Boston Overcoming Osteoarthritis through Strength Training (BOOST) study to 1)

identify participants' experiences, feelings and perspectives with exercise over two-years while participating in the BOOST study, and 2) identify factors that influenced adherence to exercise after two years.

METHODS

Design. Qualitative research methods, informed by grounded theory, were used to elicit the experiences, feelings and perspectives of participants with knee osteoarthritis. The study was approved by the Boston University Institutional Review Board and all participants provided written informed consent.

Participants and Setting. Participants were recruited from the BOOST study (Clinical Trials.gov Identifier: NCT01394874), a 2-year clinical trial examining the efficacy of a telephone-linked communication system to foster adherence to an evidence-based strength training program.⁴⁴ All BOOST participants (n=104) engaged in a six-week strength-training exercise class. Outcomes were assessed before and after the exercise class and at six-, 12-, 18-, and 24-months. Participants in the BOOST study were community-dwelling adults, age 50 years or older, with knee pain and self-reported doctor-diagnosed knee osteoarthritis. Ineligible adults included those with bilateral knee replacements, a recent intra-articular injection, limited physical activity due to pain in other body locations; those who were undergoing treatment for cancer, inflammatory arthritis, ankylosing spondylitis, or fibromyalgia; and those who were participating in a formal weight-loss program or who had regularly engaged in a lower extremity strength-training program within the previous six months.

A physical therapist or exercise scientist, accompanied by an assistant, led a one-

hour exercise class conducted twice a week for six weeks, with up to 10 participants. The exercise class included: i) postural-awareness training, ii) a walking warm-up followed by side-stepping exercises, iii) progressive strengthening exercises⁴² with a goal of achieving "somewhat hard" level of intensity⁴³ progressively, iv) instruction to complete exercise logbooks, and v) group cool-down stretches. Individual attention by instructors to foster proper body alignment was inherent throughout the program. Participants rotated between exercise stations at their own pace while engaging with other participants and receiving feedback from the instructors. In addition to the two supervised classes, participants performed the exercises at home once weekly. For home use, participants were provided ankle weights adjustable from 1-to 20-pounds, an illustrated exercise-instruction book containing additional arthritis-self-management information, and an exercise logbook. Upon completion of the classes, participants were advised to perform the home program on three non-consecutive days per week and were randomized into the intervention or attention-control groups.

The control group received an automated monthly non-interactive recorded telephone message reminding participants to continue their strength training program three times a week and to record their exercises in their logbooks. The intervention group received the same monthly non-interactive recorded telephone message and calls from an automated telephone-linked communication (TLC) system, BOOST-TLC, which was designed to enhance adherence to the prescribed BOOST exercise program. The BOOST-TLC program delivered tailored exercise motivation messages with a recorded human voice emulating counseling conversations based on prior information provided by

participants in previous phone contacts. These pre-programmed calls were specifically developed for the BOOST study guided by principles of Social Cognitive Theory and the Transtheoretical Model of Behavior Change. The BOOST-TLC calls occurred twice a month for six months and then once a month for 12 months.

For this ancillary study, participants were purposively sampled based on study arm, sex, race, age, and level of adherence to the exercise program. Invited participants were identified by the BOOST project coordinator and contacted and enrolled by the first author (AL). Adherence was ascertained from the 18-month BOOST assessment, using a single item question asking participants to rate their level of adherence to the BOOST home exercise program for the prior three-months.⁴⁴ Anchors to the item were zero (no exercise) and 10 (all BOOST exercises were performed as prescribed). We categorized adherence into three groups: 1) low adherence (zero to three), 2) medium adherence (4–6), and high adherence (7–10).

Participants also completed the Western Ontario McMaster Universities Osteoarthritis Index (WOMAC) pain and physical function subscales⁴⁵ and a demographic questionnaire.

Data collection. Interviews were conducted by AL after the 24-month assessment for the BOOST study. The interviewer was unaware of the participants' adherence level at the time of the interview. The interview questions encouraged participants to share their views about their experience in the BOOST study, and their impressions about exercise adherence over a long-term period (Appendix A). The interviews were audio recorded and completed between June 2014 and September 2015. NVivo™ (version 11.2.2, QRS

International) software was used to organize and support data analysis.

Data analysis. A professional service transcribed the audio recordings of the interviews.

The interviewer verified the transcriptions of the audio-recordings for accuracy by listening to the recordings and made changes to transcripts if necessary. This verification process provided an initial broad understanding of the data. Grounded theory principles informed data analysis.⁴⁶ First, the interviewer used line-by-line coding to develop initial codes that reflected participants' perspectives about their experiences with the BOOST program as well as their perspectives about more general exercise behaviors over the 2-year follow-up. Some examples of the initial codes include beliefs about exercise, motivators to exercise, and home exercise ability. Further details of these initial codes are provided in Table 1. A second analyst — a physical therapist with greater than 10 years of experience working with adults having knee osteoarthritis — reviewed the transcripts line-by-line for one-third of the participants and completed initial coding using a code book developed for the analyst by the first author. The second analyst and first author compared findings and discussed any discrepancies or assumptions related to the interpretation of the data with the goal of reaching consensus. Focused codes and conceptual categories were developed by exploring patterns and nuances in the initial codes that reflected participants' experiences regarding motivation toward exercise and home exercise abilities. Some examples of the focused codes include pacing, social comparison and professional instruction. Table 2 provides further details of these focused codes. Finally, to identify factors that appeared to influence adherence to exercise among participants in the BOOST study, after two years, we compared the participants who

reported high adherence to the BOOST exercises with those who reported low adherence. Due to small numbers of participants in the medium adherence category (n=5), we compared just the low- and high-adherence groups. We re-reviewed the initial codes containing the largest amount of data relevant to adherence to exercise, for example, the home exercise ability initial code. Data were arranged into high or low adherence columns for side-to-side comparisons. We then re-examined the focus codes to identify commonality among participants with high adherence and those with low adherence using a color coded chart for comparison (Appendix B). Using a similar analysis process, we explored differences between participants in the intervention group compared to those in the control group.

Trustworthiness. Several steps were taken to enhance the trustworthiness of this study. An administrative assistant selected interview participants to eliminate potential selection influence by the first author, who worked repeatedly with the research participants during the BOOST study potentially forming opinions of participants. A second analyst verified initial coding for a subset of the data. Once the initial conceptualization of the data was completed, we invited two interviewees to share their views regarding the interpretation and conceptualization of the data. These interviewees affirmed that overall the visual representation of the findings captured their experiences and perspectives and based on a comment, we changed vocabulary to enhance clarity to telephone technology. Although we engaged in a multi-layered analytic process we present the findings through our inescapable experiences as practitioners and researchers.

FINDINGS

Twenty-nine participants in the BOOST trial were invited to be interviewed. Four individuals did not participate, two individuals agreed to the study but were not well enough to attend the final BOOST assessment, one agreed but was unable to complete the interview due to time constraints, and one refused. A total of 25 interviews were conducted.^{36,47} We identified no new information relevant to the study objectives from the last five participants and determined data saturation was reached. The age of participants ranged from 57 to 79 years with a mean of 67 years, 21 were female and 14 were in the intervention group. Self-reported adherence levels were evenly distributed among participants. The duration of the interviews ranged from 28 to 61 minutes with a mean of 41 minutes. Further details of participants' characteristics are provided in Tables 3 and 4.

Participants' experiences, feelings and perspectives with exercise over the two-years while participating in the BOOST study were amalgamated into three overarching themes that represent their beliefs i) monitoring, ii) knowledge of how to manage their own exercise behaviors, and iii) benefits of exercise. The data suggest that participants who reported high-adherence had self-determination and self-efficacy, whereas those who reported low-adherence were ambivalent about the benefits of exercise and had a desire for more social support. See Figure 1 for a visual representation of the findings. The analysis exploring differences between participants in the intervention group as compared to those in the control group showed no differences.

Summary of overarching themes – Beliefs about the benefits of the features of BOOST

Monitoring

Many aspects of monitoring — defined as watching or checking over a period of time for a special purpose⁴⁸ — were provided in the BOOST study. Specifically, participants were monitored during the exercise class by instructors and by pre-determined automated telephone calls provided after the exercise class. Additionally, participants monitored each other during the exercise classes. Two facets were valued by participants: monitoring during the group exercise session and monitoring through telephone technology.

Group exercise

Participants valued watching others in the exercise class observing a range of exercises being performed and coping abilities among peers. For example, Suzie reported: “I liked the camaraderie, hearin’ from other people who were experiencing similar problems...it gave me the motivation to also keep doin’ what I was doin’ to stay active”. Suzie expressed her appreciation of the inherent social support discovered during the exercise classes that motivated her to keep exercising.

Seeing others making improvements, and comparing oneself to other group members gave participants motivation to continue exercising. For example, Carlotta told us: “I could see where I was, as opposed to where other people were. And I could see how we were coming along, as the program progressed. Who seemed to be doing much better than when they first started, and then it [observing other group members] gives

you incentive to keep on with what you have to do.”. Another participant, Sue, explained her perspective of social comparison: “Well, some people would, say... ‘I got fifteen pounds of weight on my [leg],’ and I said, ‘Oh my gosh, how do they do it? I can’t even do four.’ [laughs] ‘And they can do that many?’ I said, ‘Oh, my, maybe I can do that too, eventually.’”. These quotes suggest that social comparison helped to motivate participants to continue exercising.

Many participants perceived an “accountable relationship” between themselves and other participants in their exercise group. As an example, Jason simply stated: “Well, it’s a commitment, and if you don’t show up, then the group notices.” This statement suggests he felt accountable to the group, and perceived that participants were monitoring each other's attendance, which in turn motivated them to exercise.

Participants reported that they valued the instructors’ expertise in using a client-centered approach. In the group environment, each participant received individual attention so he or she could achieve optimal musculoskeletal alignment while performing his or her exercises. Emphasis on the proper way to perform each exercise with recurring personal feedback during the six-week exercise program provided participants with confidence to exercise safely on their own. For example, one participant, Jenny explained:

I knew exactly what the expectation was in terms of getting it [the exercise] done correctly and for safety’s sake. I certainly didn’t want to be injured. So just being here with you guys watching closely... the movements that I was making, correcting them when [they] needed to be corrected, constantly—it made a big difference, ‘cause to go home and not be sure exactly how to do ... the steps or

the movements for safety's sake, would've been a cause for concern, I would be like, 'Am I doing this right?' You know, and that in itself for me is stressful. I don't want stress. (Jenny).

Jenny described an appreciation of being closely monitored by the instructors because it enhanced her confidence that she was exercising safely when the instructors were no longer monitoring her.

Telephone technology

Regardless of whether the participant was in the intervention or the control group, telephone technology at home after the group program was valued. Participants endorsed the telephone calls as a source of motivation and accountability to adhere to the exercise program, and many described favorable feelings of being connected and supported by the team of people who provided the exercise program. Participants described being motivated to continue with their exercises as a result of receiving the telephone calls. For example, in response to being asked about her ability to adhere to her home exercises one participant, Rose, exclaimed "Knowing that I'm gonna get that phone call!". During the interview Rose expressed her perception of feeling judged, "getting graded", when interacting with the BOOST- TLC. Rose's desire to achieve a favorable judgment motivated her to perform the exercises. Although, some participants expressed a dislike for automated telephone technology, they appreciated being reminded to exercise. For example, Brenda who was in the control group, conveyed "Even though I don't like it, [automated telephone calls] [laughs] it's a good motivator".

Participants reported that the goal setting feature built into the BOOST-TLC

technology contributed to accountability. During the BOOST-TLC call, participants entered the number of days they had exercised during the previous two weeks, which was compared to the goal the participant set at the *previous* BOOST-TLC call. One participant, Jess, described her perspective:

“It [BOOST-TLC] would ask you more specific questions, how many times did you exercise, what were your goals, and I thought that was good. It was kind of a pain in the neck sometimes[laughs]. I said ‘Oh, I don’t feel like doing this,’ but I thought it was good, because it made me think, ‘OK. When am I gonna exercise?’”.

Several participants, who were routinely performing the exercises, reported that they were not motivated to exercise by the telephone calls. However, they valued the feeling of being connected with the research team as a result of receiving the telephone calls, two participants reported: “... it [the telephone calls] shows that the BOOST Program cared about you. And they wanted to make sure you do your exercise, make sure you was followin’ the protocol, it was very beautiful.” (Rebecca, intervention group); George, who was in the control group, reflected on the calls, stating, “So they [laughs], they remembered me”. These quotes suggest a favorable response to being remotely connected to the research team through the automated telephone calls.

For many participants, engagement with the BOOST-TLC waned over time. The coaching and counseling content became redundant and answering the same questions became tiresome. One woman, Susan stated "At the beginning, it's very encouraging, but after a while, it's kind of, to me it's kind of tedious". Participants described the process of interacting with the BOOST-TLC to be very repetitive and over time new knowledge acquisition ceased, diminishing the value of using the BOOST-TLC.

Knowledge of Exercise

The set up in the clinic room with different stations for exercising, permitted the participants to gain knowledge and progress with the exercise program at a graded self-selected pace. Exercising at a self-selected pace enabled participants to perform exercises within their boundaries, augmenting self-efficacy and self-determination related to exercise. For example, Dee explained: “When you take one step at a time, everybody’s levels of course will probably be different, but everybody works at their own pace, basically... You do it [exercise] as much as you can.”. Stephanie explained her perspective on self-pacing this way: “...while we were in the group each person was able to proceed and progress as they were physically able and mentally able, yet you still got the individual attention to be able to judge your progress”. These quotes suggest that participants developed the knowledge to self-manage their exercise program using autonomous decisions toward a graded adaptive approach optimizing exercise performance within their personal tolerance. Furthermore, as previously described by Jenny, meaningful knowledge of exercises fostered confidence with performing exercises safely.

Additionally, Anne described applying her knowledge gained during the BOOST study to modify the performance of her exercises and fit them into her lifestyle:

"...if you didn't have time to do all of 'em, you could just start some of them during the day, just as long as you finished it during the day, and I know I would get tired, and I said, 'Oh no. I forgot to do the lunges,' you know, that was the last thing, OK. But you know, if I started out in the morning [leaving her home],

I was doing them everywhere ... I would go quilting, and ... I see the stairway [to perform step-up exercises]".

Perception of Exercise Benefits

For the majority of participants, perceived benefits of performing the exercises included relief from pain and improvement in physical function. Furthermore, as a result of pain and functional improvements, participants described satisfaction about being more independent in their daily lives. Susan reported she felt stronger as a result of exercising. Engaging with her exercise program provided her with the perceived benefit of having more stamina for housework and better functional ability to independently take her grandson to play in the park

"... [I] could do more work in the house, and OK, maybe go out and take my grandson, to the park by myself. No need to wait for my husband. If my leg is not strong enough, I have to wait for my husband, 'cause I'm afraid that --he's running around, [I] won't be able to catch him."

Beliefs about Adherence at Two-years

High-adherence

Participants with high-adherence described processes that are consistent with self-determination—i.e., having intrinsic control of exercise behaviors. For example, Lyndsey stated "if you want something bad enough you do it". Lyndsey's statement reflects choosing to exercise without any need for external motivation.

Strategies used by participants with high adherence included establishing space in their home to exercise, forming exercise routines and/or embedding the exercises into their lifestyles. For example, Rose explained: "It was an easy process for me, because I

had everything laid out. I kept my bag right there in the kitchen, so while I'm in the kitchen, before I start my day, I would just do my exercises".

Additionally, participants with high-adherence described processes that are consistent with having self-efficacy. For example, George stated "... and it seems like everything I did here [during the exercise class], I was able to do at home with no problems". George reported mastery of performing his home exercise program conveying a strong sense of self-efficacy about his ability to exercise. Dee spoke of initially feeling intimidated during the exercise classes, however, she persevered:

"I found it a little bit intimidating at first [the exercise class], 'cause it was like an obstacle course, where you had to do this, then you went from that to a [another] thing...I'm saying, 'Oh gosh, I can't do this. This is a bit much.' But then I said, 'But no. Let me give it a shot and just try to do it,' and it's not like I gotta be vigorous with it, just take my time, go at it."

Dee's ability to motivate herself to continue attending the exercise class, despite her initial perception of the daunting task, is concordant with self-efficacy.

Low-adherence

Participants with low-adherence described ambivalent perspectives about exercise results. Stephanie stated: "I think the other reason I probably fell down a little bit on doing the work, the exercises, was that I think after a point I wasn't convinced that even though I knew strengthening would help, I wasn't convinced that it would allow me to change my lifestyle back to what it used to be.". Stephanie acknowledged that strengthening exercises would be beneficial, however, she expressed uncertainty regarding the ultimate value of exercise.

Additionally, participants with low-adherence as compared to participants with high-adherence, described a greater desire for external social support such as an exercise partner and/or supplemental exercise classes. They suggested that an exercise partner would enhance motivation and accountability to doing the exercises. Audrey described her dependence on external support stating: “Because it makes a difference. It’s more motivating when you’re doing it [exercise] with someone else. It’s easy to go back to your regular routine of doing nothing. I mean, if it’s just me, I don’t, I don’t care about me. [laughs] But it’s different, I’d care about someone else.”. Audrey expressed how her action to exercise is greater when there is an external motive, in this case having a commitment to someone else.

Participants suggested that additional exercise classes would provide another opportunity to have their exercises monitored by the instructor, and to learn from the experiences of other participants and make social comparisons. For example, Bernadette recommended: “... a suggestion might be to have like a reunion... Do the exercises, ...I guess, hearing people’s experiences with the exercises, seeing if we were doing them right, tweaking them, you know, getting some feedback.” In another example, when discussing the home exercises, Carlotta expressed:

"I missed the group. Maybe sometimes we could have, during the interim, have one group study again, come in and see how everybody’s doing, and then go back. So in between the phone calls, every now and then there’s ... I don’t know, quarterly or whatever, just come in that one time. See who’s havin’ any difficulties, and how you can change that."

These data suggest that participants with low-adherence at two-years, did not achieve sufficient mastery of the exercise program to feel confident in their ability to sustain exercise without having external support.

DISCUSSION

The objectives of this study were to explore participants' experiences, feelings and perspectives with exercise over the two-years while participating in the BOOST study and to identify factors that influenced adherence to exercise among participants in the BOOST study after two years. Three themes reflecting participants' beliefs about benefits of the features of the BOOST intervention and exercise were identified: i) monitoring, ii) knowledge of exercise and iii) perceived benefits of exercise. Factors related to high- adherence to the BOOST exercises included self-determination and self-efficacy. Factors related to low-adherence included ambivalence about exercise, and a desire for more social support and expert instruction.

Participants reflected that monitoring — e.g. "somebody is watching me" — occurred during the group exercise program as well as in both types of follow-up telephone calls. This type of external monitoring has been shown to increase self-awareness and foster more truthful behaviors.⁴⁹ External monitoring (i.e. supervision) showed greater effects in exercise walking distances compared to non-supervised walking programs.⁵⁰ Exercising in the presence of external monitoring among peers in a group setting may allow for social comparison which may facilitate an individuals' desire to perform exercises with the best technique possible and carry-over to using optimal exercise technique at home leading to better functional outcomes. Results from studies

comparing group to individual exercise programs show some support for better outcomes in pain and physical function using group intervention; however, these studies had small sample sizes and results failed to reach statistical significance.^{51,52}

Monitoring through the use of automated telephone technology seemed to promote motivation and accountability to exercise and receiving the calls fostered a recurring psychological connection to the research team. Feeling a connection with a physical therapist has been shown by Campbell et al.³⁶ to be associated with high levels of adherence to exercise when patients were still attending physical therapy treatment. For some individuals, it is conceivable, that using telephone technology to provide a recurring psychological connection to the physical therapist can foster greater self-determination behaviors and long-term adherence to exercise when formal treatment has been completed. On the other hand, two studies show no benefit of telephone support on long-term adherence to exercise.^{53,54} A systematic review and meta-analysis on adherence to exercise after a supervised exercise program among adults with chronic diseases showed no additional benefit to telephone follow-up compared to center based follow-up.⁵⁴ Bennell et al. investigated the effectiveness of telephone coaching over six-months in adjunct to physical therapy treatments among adults with knee osteoarthritis.⁵³ Results for the primary outcomes of pain and function showed no additional benefit of telephone coaching. Home exercise adherence, a secondary outcome, was significantly greater among participants while they received the telephone coaching, however, there was no added benefit at the 12-and 18-month follow up. This model of using telephone coaching is different from the model used in the BOOST study. The BOOST study used

automated telephone systems over the course of two years after the exercise class was completed; Bennell et al. used trained coaches for their telephone intervention over the first 6-months, simultaneous to physical therapy intervention. More research is needed on how and when telephone interventions may effectively promote adherence to exercise.

Knowledge of exercise occurred through formal class instruction, repeated practice that strengthened learning, and through the opportunity to consider the viewpoints of others while exercising in a group environment. Vicarious experience — monitoring others performing challenging activities — is recognized as a source of information that promotes self-efficacy.⁵⁵ In addition, gaining mastery over the complex situation may have contributed to participants' comfort with modifying their exercises and environments to meet personal, physical and social needs.

Knowledge of exercise has been linked with increased adherence among adults with knee osteoarthritis¹⁴ as well as other conditions among the general aging population.⁵⁶ Knowledge may be particularly important for adults with knee osteoarthritis in order to debunk common myths including that osteoarthritis is a normal part of aging and that exercise is harmful to the arthritic joint. Lastly, knowledge can provide individuals with information on the types of exercises and the skills to perform them safely promoting self-efficacy.

Many features of the BOOST study incorporated components of the Social Cognitive Theory, a widely used theory in health promotion that recognizes the reciprocal interactions of the environment, person, and behavior.⁵⁷ For example, the

initial sessions included teaching participants how to complete the exercises with practice, modeling and real-time feedback by exercise experts.⁵⁸ The exercise class was conducted in a supportive group environment among peers that enabled social comparison. Self-regulation — internal monitoring— is inherent to strengthening exercises because one has to pay attention to exercise effort and progression of resistance intensity.⁵⁹ Exercise logbooks were provided to help participants realize their exercise progression and achievement of goals.

As noted by other researcher, self-determination and self-efficacy may be essential for adherence to exercise.^{37,60} Central to the self-determination theory of motivation are the concepts of autonomy, competence and relatedness needs.⁶¹ How these needs are met among patients may influence the strength of self-determination. Autonomy refers to an individual's need for choices, using volition for actions. Competence refers to the need to successfully use ones capacity to achieve a desired outcome; and relatedness refers to the need of feeling connected to others, respected and understood.^{37,62} Addressing these needs have been empirically shown to foster motivation toward long-term adherence to exercise.⁶² Findings from our study, consistent with the findings of Kinnaefick et al.,³⁷ who examined adherence to a four-month walking program among sedentary adults, showed participants with high-adherence described greater autonomy and competence about completing exercises compared to those with low-adherence who articulated greater relatedness needs including a desire for external supports.

Physical therapists can help patients develop stronger self-determination.

Autonomous needs can be addressed by understanding patients' perspectives, providing choices about treatment and goals, and appreciating their choices.⁶² Competence needs can be addressed by repeatedly supervising exercise performance assuring patients they are using proper techniques to promote success, and confidence in their ability to self-manage their exercise behaviors. Relatedness needs can be addressed by fostering a positive therapeutic relationship. In addition, the findings support the use of group exercise and automated telephone technology, both of which may be used to address competence and relatedness needs of patients with knee osteoarthritis.

The importance of self-efficacy for endorsing sustained behavior change, specifically among adults with chronic conditions, is well established in the literature.⁶³ Physical therapists can use the psychosocial influences of self-efficacy to enhance functional outcomes for their patients, for example, highlighting patient's exercise performance accomplishments.⁶⁴ The findings of this study adds to the evidence of acknowledging and fostering self-efficacy among adults with knee osteoarthritis.

To our knowledge, this is the first study to explore perspectives of exercise, adherence to exercise and automated telephone technology among adults with knee osteoarthritis over two-years subsequent to participating in a group strength training program. We recognize several limitations to the study. All participants were enrolled in a RCT and volunteered to attend a group exercise class indicating motivation to engage in an exercise program, therefore, findings may not be generalizable to all adults with knee osteoarthritis. In addition, the interviewer (AL) worked with participants as a research assistant in the parent BOOST study and participants may have reported what was

expected of them. Lastly, the findings are based on self-reported adherence determinates while participants were actively engaged/monitored by the BOOST study protocol.

Behaviors and perspectives of adults while participating in research can be different from those of the general population,⁴¹ additionally, there is a risk that a person's perception of adherence to exercise is not equal to the genuine home exercise performance.

Despite these limitations, findings of this study provided important information on long-term adherence factors to strength training exercises among adults with knee osteoarthritis. A novel finding is the role of self-determination in the context of adherence to strength-training exercise over 2-years among adults with knee osteoarthritis. Implications for physical therapists include identifying patients' autonomy, competence and relatedness needs to foster intrinsic control for exercise behavior. Monitoring provided by peers and instructors during an innovative group exercise approach and by telephone technology were valued by participants and warrants further research.

Table 1.

Initial code examples

| Initial code | Code description | Example |
|------------------------|---------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | | |
| Beliefs about exercise | Any opinion or expectation about exercise | <p>"My gut feeling is the exercise program is helping me to at least maintain an ability to be physically active as I am. But I'm still getting older and deteriorating [laughs]." (Angelina)</p> <p>"All exercise is boring. These exercises are not more boring [laughs] or less boring." (Charlot)</p> |
| Motivators to exercise | Any mention of factors that motivate participant to exercise | <p>"So there's a lotta positive things coming out of just uh, taking a little short walk. If you could find a buddy, it would be fantastic though, too. That's motivating." (Audrey)</p> <p>"I wanna maintain that strength, because I know, right? When I walk around and I see everybody, all these people that are probably younger than me, and a lot younger than me, when I go to the hospital, and they're all in wheelchairs. And I wanna maintain my mobility as long as I can." (Mia)</p> |
| Home exercise ability | Answer to a question such as: What contributed to your ability to do the exercises at home? | <p>"I did the exercises [during the exercise classes], and then we were given weights and things to take home to do, and I got it, I set up a routine for myself." (Lyndsey)</p> <p>"Yeah, because I think, I saw some improvement. And, you know, like before, when we started doing the squats here...you'd want to plop down in a chair. And now you can sit down gradually, at your own pace, and I see myself sitting down like sometimes we'll be sitting in church and I just jjjjpp! I just get right up, and I said, 'Ohhh, that's pretty good.' [laughs]" (Sue)</p> |

Table 2.

Focus code examples

| Focus code | Code description | Example |
|--------------------------|---------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Pacing | Value of deciding own pace with exercise | <p>"I just feel, it's a very personal point, you just need to be aware that you have to measure it for yourself, don't let anybody push you too much."(Brenda)</p> <p>"I thought about it [doing the BOOST exercises] and said, 'I can't do this.' But then I said, 'But no. Let me give it a shot and just try to do it,' and [pause] it's not like I gotta be vigorous with it, just take my time." (Dee)</p> |
| Social Comparison | Any reference to comparing to other participants in the group | <p>"It was encouraging because some people could do it a little bit quicker than you, and some people you might think you're doing it a little quicker than they are. Not like comparing, but you could just see that there's a whole range of abilities, and you sort of start to see like that you aren't weird, or something like that". (Bernadette)</p> <p>"It was interesting to see the other people. I happened to be the strongest person [laughs]." (Jason)</p> |
| Professional instruction | Influence of having expert guidance and instructions | <p>" So I think having physical therapists around to say, 'Stand up straight,' or 'If you'd lift your leg higher, or hold it longer, or point your toe, or toes towards the ceiling,' ... I think for me, given that I'm so out of touch with my body and my muscles, and how to make it work correctly, I think that was helpful for me." (Charlot)</p> <p>"I liked the level of professionalism and commitment of the instructors. I liked that they were pleasant, they were understanding, and while our group varied in age and level of severity, I'll say they were all patient and understanding and encouraging, and that was important to me, and that made me wanna be committed to showing up for those weeks that we had to come in person." (Stephanie)</p> |

Table 3.

Summary descriptive data of participants

| | mean(SD) |
|-----------------------------------------------|---------------------|
| Age, years | 67 (6.1) |
| Body Mass Index | 31.4 (9.7) |
| | Number (percentage) |
| Female | 21(84) |
| Race | |
| White | 12(48) |
| Black | 9(36) |
| Other | 4(16) |
| Comorbidity | |
| Hypertension | 12 (48) |
| Chronic Respiratory Conditions | 5 (20) |
| Diabetes | 4 (16) |
| Heart Disease | 4 (16) |
| | |
| Participants randomized to BOOST intervention | 14 (56) |
| Exercise Adherence (range 0–10) | |
| Low (0–3) | 11 (44) |
| Medium (4–6) | 5 (20) |
| High (7–10) | 9 (36) |
| | mean (SD) |
| Exercise Adherence | 4.5 (3.6) |
| WOMAC change scores* - pain (range 0–20) | -3.4 (3.7) |
| - function (range 0–68) | -5.3 (10.7) |

*WOMAC - Western Ontario and McMaster Universities Osteoarthritis Index
 Change scores = 2-year final score - baseline score. Lower values more favorable.

Table 4.

Individual characteristics of participants

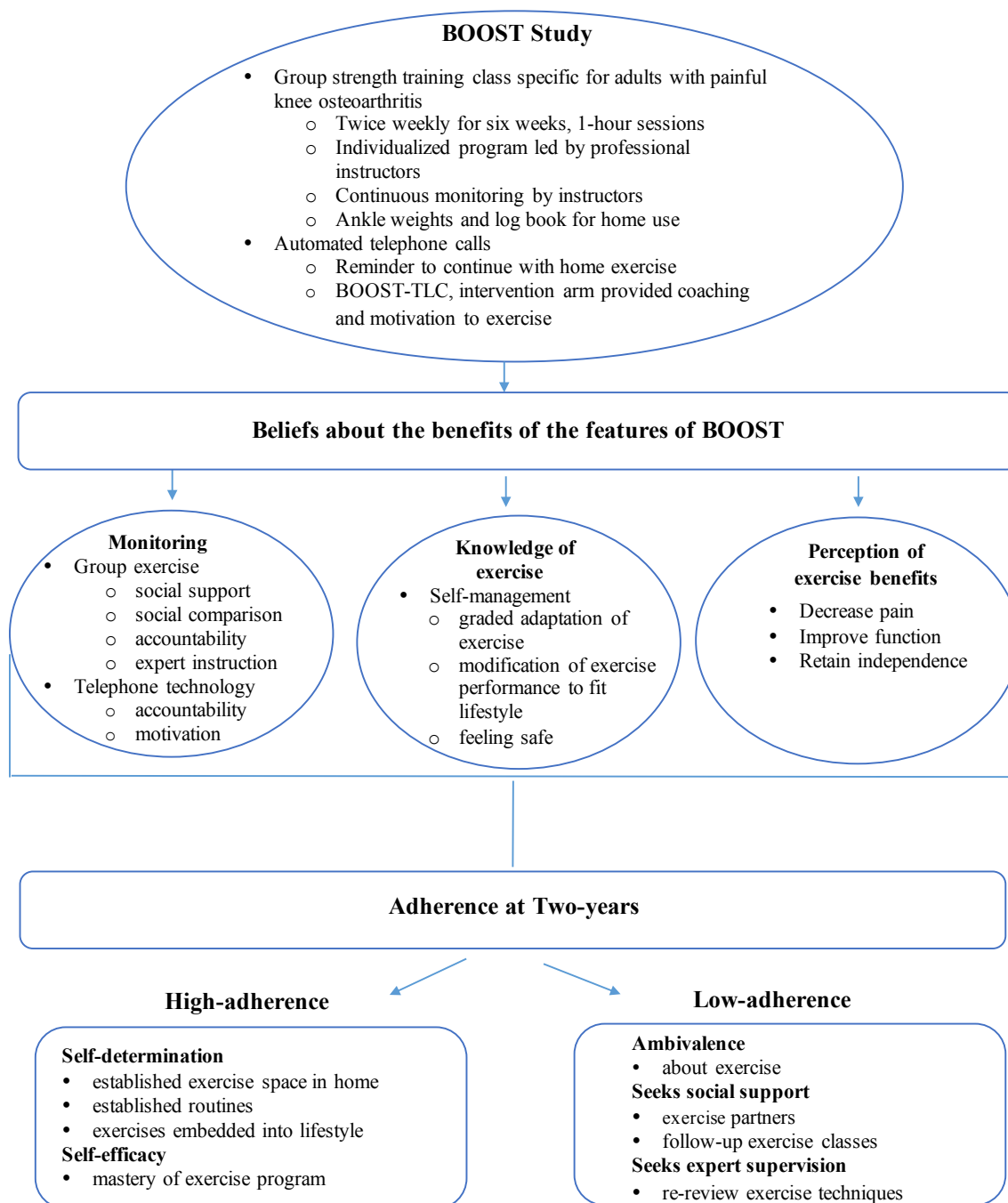
| Pseudo Name | Intervention or Control group | Age | Adherence 0–10 | MCID Pain * | MCID Function * |
|---------------------|-------------------------------------|-----|-------------------|----------------|--------------------|
| Stephaine | I | 70 | L (0) | no | no |
| Jason [†] | I | 75 | L (0) | no | no |
| Jake | C | 70 | L (0) | yes | yes |
| Francis | C | 73 | L (0) | no | yes |
| Audrey | C | 57 | L (0) | yes | yes |
| Brenda | C | 62 | L (1) | yes | no |
| Carlotta | C | 66 | L (1) | no | no |
| Bernadette | I | 67 | L (1.5) | yes | no |
| Charlot | I | 68 | L (2) | yes | yes |
| Thomas [†] | I | 68 | L (2) | yes | yes |
| Jess | I | 61 | L (3) | no | yes |
| Susan | I | 61 | M (4) | yes | yes |
| Carol | C | 68 | M (5) | yes | yes |
| Sue | I | 73 | M (5) | yes | yes |
| Phonecia | I | 78 | M (5) | no | yes |
| Mia | I | 77 | M (6) | no | no |
| Suzie | I | 66 | H (7) | yes | no |
| Dee | C | 58 | H (7) | yes | yes |
| Rose | I | 62 | H (8) | yes | yes |
| Anne | C | 67 | H (8.5) | yes | yes |
| Lyndsey | C | 69 | H (8.5) | no | no |
| Angelina | I | 79 | H (9) | yes | yes |
| George | C | 61 | H(9) | yes | no |
| Jenny | C | 61 | H (10) | yes | yes |
| Rebecca | I | 65 | H (10) | yes | yes |

[†] Indicates having a total knee replacement during the study.* MCID = Minimal clinically important difference ($\geq 20\%$ change from baseline to 2-years).

Pain = Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) pain subscale.

Function = WOMAC physical function subscale.

Figure 1.
Visual Representation of the Findings



STUDY TWO

Kinesiophobia and physical function among adults with knee osteoarthritis: Before and after strength training classes

Approximately 14 million people in the United States are clinically diagnosed with knee osteoarthritis having symptoms of pain, aching or stiffness.¹ Knee osteoarthritis, a chronic and often progressive disease, is a leading cause of disability.⁶⁵ Bone, synovial fluid, nerve, meniscus, ligaments and muscle are often deteriorated.^{2,3} Rising from a chair, negotiating stairs and walking can be markedly compromised.⁵ Exercise, a widely recommended first line treatment to improve pain and daily function among adults with osteoarthritis⁶⁻⁹ is seriously underutilized^{12,66,67}. Identifying factors that restrict movement and exercise among people with knee osteoarthritis is critical.

Kinesiophobia, or fear of movement due to pain and potential physical harm, is proposed to be an important factor restricting movement and willingness to perform exercise among adults with chronic pain,^{25,26,68} including knee osteoarthritis.^{28,69-71}

Kori, Miller and Todd developed this term in an effort to include biopsychosocial processes into the treatment paradigm of chronic pain.²² Several studies provide evidence of the benefits of exercise and cognitive interventions in ameliorating kinesiophobia, physical function and psychological function among people with chronic low back pain.^{25-27,72,73} Among adults with knee osteoarthritis, kinesiophobia is hypothesized to limit physical activity thereby contributing to movement restrictions and functional limitations,⁶⁹ however, the research is limited.

In cross-sectional studies of adults with knee osteoarthritis kinesiophobia is

negatively associated with better self-reported physical function^{28,29} and fast gait speed.³⁰

The relationship of kinesiophobia with performance-based measures of physical activities, such as stair negotiation, sit-to-stand, and ambulatory transitions, common outcome measures for research and clinical decision making are not known. These performance-based measures have been recommended by the Osteoarthritis Research Society International (OARSI)⁷⁴ for measurement of function in patients with knee osteoarthritis. A better understanding of the relationship of kinesiophobia to these performance-based measures of physical function would be useful to guide intervention approaches and outcome assessments.

Furthermore, little is known as to whether kinesiophobia changes after exercise among adults with knee osteoarthritis. In a secondary data analysis from a randomized controlled trial of an individual, evidence-based exercise program, Fitzgerald et al. showed adults who responded to the exercise program (defined as $\geq 20\%$ change in self-report pain and function) had greater improvement in kinesiophobia at 2-months compared to adults who did not respond to the program.⁷⁵ This finding, however, may reflect a differential bias since both kinesiophobia and physical function were ascertained by self-report in this study.

The purpose of this study was to examine the relationship of kinesiophobia with commonly used knee osteoarthritis performance-based measures and whether kinesiophobia changes after an evidence-based exercise class. Specifically, our aims were to determine: (1) if kinesiophobia was associated with physical performance measures at baseline, (2) if kinesiophobia improved after a six-week strength training program and (3)

if change in kinesiophobia was associated with change in pain and function among adults with knee osteoarthritis participating in an evidence-based strength training program. We hypothesized that kinesiophobia would be associated with performance-based measures. Furthermore, we hypothesized that kinesiophobia would improve after the exercise class and improvement in kinesiophobia would be associated with improvement in pain and function.

Methods

Design

This study used pre-randomization data from a large randomized controlled trial, the Boston Overcoming Osteoarthritis through Strength Training study (BOOST - ClinicalTrials.gov, Identifier: NCT01394874). The BOOST study was a randomized controlled trial of the efficacy of a telephone linked-communication system to improve 2-year adherence to a prescribed evidence-based strengthening program following a six-week strength training class at Boston University. The current analysis used data collected before and immediately after the exercise class, prior to randomization into experimental and control arms, among people who completed a kinesiophobia assessment. All participants provided written informed consent to participate in the study, which was approved by the Boston University Institutional Review Board.

Participants and setting

Participants consisted of community-dwelling adults, age 50 years or older, with knee pain and self-reported doctor-diagnosed knee osteoarthritis. Ineligible adults included those with bilateral knee replacements, a recent intra-articular injection, limited

physical activity due to pain in other body locations; those who were undergoing treatment for cancer, inflammatory arthritis, ankylosing spondylitis, or fibromyalgia; and those who were participating in a formal weight-loss program or had regularly engaged in a lower extremity strength-training program within the previous six months.

The exercise classes were one-hour sessions conducted twice a week for six weeks. Classes were led by either a physical therapist or an exercise scientist, accompanied by an assistant. The classes included: postural awareness advice, a walking warm up, side-stepping exercises, strengthening exercises,⁴² individual attention to proper mechanical alignment, and cool-down stretches. Participants rotated between exercise stations at their own pace while engaging with other participants and receiving feedback from the instructors. Participants were asked to perform the exercises at home once weekly in addition to the two supervised classes. Ankle weights adjustable from 1- to 20-pounds, and an illustrated exercise-instruction book containing additional arthritis-self-management information was provided for home use.

Data collection

Data were collected from participants before and after the six weeks of exercise classes. Kinesiophobia was measured using the 17-item Tampa Scale of Kinesiophobia (TSK).⁷⁶ The TSK includes statements such as "I'm afraid I might injury myself if I exercise." Response options ranged from (1) "strongly disagree", (2) "disagree", (3) "agree", to (4) "strongly agree". Scores were summed to provide a total score ranging from 17 to 68, with higher scores indicating a higher level of kinesiophobia. Reliability and validity values for the TSK have been established in patients with chronic low back

pain.⁷⁷

Performance-based measures included timed-up-and-go, sit-to-stand and stair negotiation. Participants were instructed to perform each test as quickly as possible while still feeling safe and to refrain from using their arms to push up from the chair or hold the stair railing. If a participant used his/her arms for any of the performance-based measures, they were instructed to use their arms in the same manner for the follow-up testing. All performances were timed, measured to the nearest one-hundredth of a second and performed according to protocol.

For the timed-up and go (TUG) test⁷⁸ participants began seated in a standard chair with his/her back in contact with the chair back. Participants were instructed to stand, walk to a line three meters away, turn, walk back to the chair and return to sitting. Participants were given an untimed practice trial. Test timing commenced on the word "go" and finished once the participant was seated with his/her back against the chair. The faster time of two trials was used for data analysis.

For the sit-to-stand test⁷⁹ participants were seated with his/her arms folded across the chest, with his/her back in contact with the chair back. Participants were instructed to stand fully erect and return to the seated position. Participants were given a one repetition practice trial. Timing commenced on the word "go" and finished once the participant was seated with their back against the chair. Participants completed five repetitions of sit-to-stand, rested 90 seconds, and then repeated the test for ten repetitions.

For the stair negotiation test participants stood with their toes placed on a delineated line on the floor in front of the stairs. Participants were instructed to place one

foot on each step (alternating pattern) to ascend 10 steps, turn, and descend the steps. Participants were encouraged to refrain from using the hand rail. The fastest time of two trials was used for data analysis.

Quadriceps strength was measured using the Biodex System 3 (Biodex Medical Systems, Inc. Shirley, NY). Isokinetic testing utilizing a pre-determined maximum constant velocity of 60 degrees per second was used. The Biodex apparatus was adjusted to fit each individual participant per Biodex protocol. Proper stabilization of the participant to restrict accessory trunk and arm movements was implemented throughout testing. Participants completed practice repetitions using submaximal effort. For the test, participants were instructed to perform maximum contractions for five repetitions of knee extension and flexion. For data analysis, we collected peak torque outcomes in foot/pound units and divided the peak torque by participants' weight in pounds to adjust for outcome differences due to body weight.⁸⁰

Pain and function were measured using the Western Ontario McMaster Universities Osteoarthritis Index (WOMAC), a widely used questionnaire in osteoarthritis with reliable and valid psychometric properties.⁴⁵ The five-point Likert version with choices ranging from "none" (0) to "extreme" (4) was used. Scores were used with each subscale summed. Pain scores could range from zero to 20 and physical function scores could range from zero to 68.

Power

Sixty-two participants had TSK scores at baseline, with 55 of these participants having TSK scores both before and after exercise class. The TSK assessment was added

to data collection after the study initiated; hence, not all BOOST participants completed the assessment. The TSK assessment was, however, administered to consecutive participants once it was added. This sample size was estimated to provide 80% and 90% power to detect partial correlations of .38 and .43, respectively. A previous study found a partial correlation value of 0.53⁸¹, and our sample size would allow greater than 95% power to detect a correlation of this magnitude given a significance level of 0.05, while accounting for four additional predictor variables.

Data analysis

Descriptive statistics were performed to establish the distribution of our baseline variables. Means and standard deviations were used for continuous variables; frequencies and percentages were used for categorical variables. Linear regression was used to examine the association between kinesiophobia and physical performance measures. Analyses were adjusted for sex, age and baseline pain. Change in kinesiophobia over the six-week exercise class was evaluated using the paired t-test. The association between change in kinesiophobia and change in pain and function was evaluated using linear regression. To determine change scores, we subtracted before exercise values from after exercise values. Sensitivity analyses were performed to explore the effect of three participants who did not perform the 10-repetition sit-to stand test; we examined the descriptive data and used multiple imputations to fill in the missing values. A significance level of 0.05 was used for all statistical tests, P-values were not adjusted for multiple comparisons. SAS software, version 9.3 (Cary, NC) was used for analyses.

Role of the Funding Source

This study was supported by the National Institute on Disability Independent Living, and Rehabilitation Research (90RT50090).

Results

The mean age of the participants at baseline (n=62) was 63; 48 were female and 28 were non-white. (See Table 5). The mean TSK score at baseline was 32 and the mean change in TSK after the exercise class was -0.58. The mean baseline scores for stair negotiation was 16.3 seconds, sit-to-stand 5 repetitions was 15.1 seconds, sit-to-stand 10 repetitions was 29.6 seconds and quadriceps strength was 0.29 foot-pounds/body weight. The mean baseline WOMAC pain score was 7.4 and WOMAC function was 20.5.

Baseline kinesiophobia was positively associated with slower baseline times on the stair negotiation (slope 0.53, SE 0.23, 95% CI 0.08 to 0.98 p= 0.02) and the 5 repetition sit-to-stand (slope 0.20, SE 0.09, 95% CI 0.01 to 0.39, p= 0.03). The association between kinesiophobia and the 10 repetition sit-to-stand and the TUG did not attain statistical significance (See Table 6). Kinesiophobia was slightly reduced after the exercise class but did not attain statistical significance (mean change -0.58, SE 0.79, 95% CI -2.17 to 1.01, p=0.47) (See Tables 7 and 8).

Change in kinesiophobia was not associated with change in physical performance measures after the exercise period (See Table 9); however, change in kinesiophobia was associated with change in self-report WOMAC physical function (slope 0.54, SE 0.22, 95% CI 0.09 to 0.99, p=0.02). The association of change in kinesiophobia with change in WOMAC pain was modest with a trend towards significance noted (slope 0.14, SE 0.07,

95% CI -0.01 to 0.30, $p=0.07$).

Sensitivity analysis exploring the discrepancy between the 5 repetition and 10 repetition sit-to-stand results showed that all three people had high values for TSK and two people had some of the longest times for the 5 repetition sit-to-stand measure (Appendix C Table 1). Multiple imputation for the missing 10 repetition sit-to-stand values (Appendix C Table 2) showed the baseline association with TSK to be stronger and closer to significance (slope 0.32, SE 0.18, 95% CI -0.49 to 0.69, $p=0.09$, $r^2=.05$). Furthermore, the imputed 10 repetition result showed a greater association to TSK when compared to the 5 repetition (slope 0.32 and 0.20, respectively).

Discussion

Our study showed that among adults with knee osteoarthritis baseline kinesiophobia was positively associated with slower stair negotiation and sit-to-stand measures. However, in contrast to our hypotheses, kinesiophobia did not significantly change after the 6-week exercise program. Furthermore, examining the associations of change in kinesiophobia with change in pain and physical function demonstrated positive associations with self-report measures and not with physical performance measures.

OARSI recommendations of performance-based measures for research and clinical decision-making include stair negotiation, sit-to-stand and ambulatory transitions (i.e. TUG) and should be used routinely for outcome assessment.⁷⁴ Our finding that kinesiophobia is associated with stair negotiation and sit-to-stand performance, two important functional activities known to be impacted by knee osteoarthritis⁵ and commonly used as outcome measures suggests that these additional performance-based

measures may be relevant assessments, particularly when examining the relationship between kinesiophobia and performance-based outcomes. In contrast, the TUG was not associated with kinesiophobia which may indicate the measure is not optimal when examining the relationship between kinesiophobia and performance-based outcomes. A previous study of people with knee osteoarthritis using a 30-meter walking distance showed fast walking speed was associated with kinesiophobia; however, walking at normal and intermediate speeds were not.³⁰ It is possible that the administration of the TUG which involves standing from a chair, walking a short distance turning around and returning to the chair does not allow participants enough ambulatory distance to be associated with kinesiophobia.

Importantly, kinesiophobia did improve after the six-week exercise program but did not attain a statistical significance and our effect size for change is low (Appendix C Table 3). Our finding is in contrast to study findings in adults with low back pain that showed significant change in kinesiophobia after exercise interventions^{26,73} and supports a finding in adults with knee osteoarthritis that showed no significant change in kinesiophobia after physical therapy.⁸² One explanation as to why we found little change in kinesiophobia was that our study was not designed to specifically recruit people with kinesiophobia and as such we had little variability in the data. People with chronic back pain generally have higher TSK scores than our population (Appendix C Table 4) and our limited variability in TSK could limit our findings. Secondly, the BOOST study was not designed to directly target kinesiophobia. Cognitive behavioral approaches²⁴, quota-based graded exercise programs^{26,27}, and physical therapy⁷³ have shown significant

improvement in kinesiophobia among people with low back pain, and it is possible that these approaches could address kinesiophobia among people with knee osteoarthritis. Furthermore, in a cross-sectional study examining kinesiophobia among adults with knee osteoarthritis, authors suggest that behavioral and psychological interventions to decrease kinesiophobia could improve physical activity.⁶⁹ To our knowledge, there are no interventional studies addressing kinesiophobia and exercise among adults with knee osteoarthritis.

Our finding that change in kinesiophobia was associated with self-report but not performance-based measures is important for several reasons. Our findings could shed some light on this discrepancy. The discrepancy between self-report and performance measures suggest both can be valuable for obtaining a more thorough comprehension of patients'/participants' perceptions and their capacity toward functional movements. Furthermore, the findings from this study show moderate correlation between change in WOMAC physical function subscale and change in TSK and a weaker correlation with change in WOMAC pain, suggesting perception of function could be more closely related to fear of movement than to perception of pain.

There are limitations to our study. This study was a secondary data analysis and was not necessarily designed to address the primary aims of this study. Second, all participants volunteered to attend a group exercise class indicating willingness to engage in exercise, therefore, results may not be generalizable to other adults with knee osteoarthritis. Third, our small sample size was limited and reduced our ability to detect small changes and associations.

Nonetheless, this research provides important new information. Among adults with knee osteoarthritis, kinesiophobia was associated with negotiating stairs and rising from a chair, two critically important functional activities commonly restricted by osteoarthritis. Future research addressing the impact of kinesiophobia and efficacy of interventions to modify said impact is warranted.

Table 7. Descriptive data for TSK change

| TSK n=55 | Mean | Standard Deviation | Range |
|-----------------------|------|--------------------|----------|
| Before exercise class | 32.4 | 5.0 | 21 to 42 |
| After exercise class | 31.8 | 5.1 | 20 to 43 |

Table 8. TSK Paired T-test

| Mean change | Standard Deviation | Standard Error | 95% Confidence Limits | P-value |
|-------------|--------------------|----------------|-----------------------|---------|
| -0.58 | 5.89 | 0.79 | -2.17 to 1.01 | 0.47 |

Table 9. Simple linear regression of change scores

| Change score dependent variables | Change score TSK independent variable | | | | |
|----------------------------------|---------------------------------------|----------------|-----------------------|---------|----------------|
| | Slope | Standard Error | 95% Confidence Limits | P-value | R ² |
| Stair negotiation n=55 | 0.09 | 0.17 | -0.24 to 0.43 | 0.58 | 0.006 |
| Sit-to-stand 5 n=55 | 0.01 | 0.07 | -0.13 to 0.15 | 0.86 | 0.006 |
| Sit-to-stand 10 n=51 | -0.03 | 0.13 | -0.30 to 0.23 | 0.80 | 0.0013 |
| TUG n=55 | 0.01 | 0.04 | -0.06 to 0.08 | 0.77 | 0.0014 |
| Quad strength n=54 | -.003 | 0.002 | -0.007 to 0.0009 | 0.12 | 0.05 |
| WOMAC function n=54 | 0.54 | 0.22 | 0.09 to 0.99 | 0.02 | 0.10 |
| WOMAC pain n=54 | 0.14 | 0.07 | -0.01 to 0.30 | 0.07 | 0.06 |

DISCUSSION

The objective of this dissertation was to "take a new look" at long-term adherence to exercise among adults with knee osteoarthritis. We approached this objective by implementing a novel qualitative study of participants in a long-term evidence based exercise adherence clinical trial and began exploring the relationship of fear of movement—an important factor in chronic back pain— with physical function before and after a 6-week exercise class. New, potentially worthy factors were identified. First "monitoring" through technology and an expert instructor was clearly noted as a positive factor in promoting exercise adherence. Monitoring seemed to provide individuals with confidence that they were performing the exercises correctly and that 'someone' albeit a pre-programmed computer in our study, would hold them accountable in the home setting. If this finding is further substantiated in research, it is possible that interventions and clinical care approaches may need to integrate specific dimensions of monitoring in the clinic and the home setting to foster adherence to exercise.

Secondly, we found that adults who were more likely to adhere to the exercise program over two years, regardless of study arm, described factors related to internal control and self-regulation; whereas, people who did not adhere to the program were more aligned with external control. Self-determination theory may explain some of these findings. Self-determination identifies principles of motivation that foster or abate successful behavior change incorporating concepts of autonomy, competence and relatedness needs. For example, if identified, a patient with more external motivation with higher competence and relatedness needs, could be guided to find

additional social support for exercise outside of physical therapy and a plan could be made to have longer follow-up time. On the other hand, if identified, a patient with more internal motivation, associated with having more autonomy with competence and relatedness needs being met, may not require those additional interventions to foster long-term adherence to exercise and instead be guided with more individual goal setting.

Furthermore, behaviors found to be common among participants who reported high adherence to exercise were identified in study one. For example, the behavior of establishing a specific place in their home to routinely completed their exercise program, and establishing clear exercise routines. Physical therapists could suggest methods of embedding the home exercise program into patients' lifestyle. For example, one participant reported doing her step-up exercise using an outdoor curb while waiting in a parking lot. These types of behaviors that capitalize on alternative solutions to adhering to exercise could be easily promoted within physical therapy practice.

Third, we found that kinesiophobia was associated with stair negotiation and repeated sit-to-stand performance-based tests and that change in kinesiophobia over a 6-week structured exercise program was associated with perceived changes in self-reported function but not performance-based function. Thus, kinesiophobia, a concept not widely studied among people with knee osteoarthritis, may be an important factor in understanding functional outcomes and ultimately interventions to improve movement, exercise, and adherence to exercise. In theory, if a patient was fearful of movement, addressing the fear directly perhaps using cognitive behavioral approaches may alleviate the fears and improve function. These approaches are typically not part of standard

physical therapy practice but could be integrated with guidance from health psychologist.

Further research in this area is needed to identify the relationship of kinesiophobia

In summary, the "new look" of this dissertation leveraged a clinical trial to examine the experiences participants had i) attending a strength training class, ii) using telephone technology and iii) adhering to a strength training program for 2-years; and examined kinesiophobia in relation to function among adults with knee osteoarthritis. Results of this "new look" provide a new foundation for further research. For example, our research showed that older adults with knee osteoarthritis valued telephone technology, which suggests that this mode of delivery may be possible. Furthermore, our results show that self-determination theory may be a beneficial framework to use when designing studies about long-term adherence to exercise. Lastly, we showed kinesiophobia was negatively associated with performance-based functional movement among adults with knee osteoarthritis. Future research on how to modify kinesiophobia to improve functional movement and/or promote exercise could potentially lessen the burden of disability that is associated with knee osteoarthritis.

APPENDIX A

Semi-structured interview questions (*indicates prompts)

1. First, tell me what motivated your interest to sign up for the BOOST study?
2. What did you hope when you decided to participate in the study?
3. Tell me about your experience with the BOOST study.
 - * any part/aspect/feature of BOOST experience that stood out?
 - * particularly useful?
 - * particularly not so useful?
 - * what didn't you like?
4. Tell me about your experience with the exercise classes themselves.
5. There were other features of the BOOST study, what did you think of those?
 - * BOOST-TLC
 - goal setting
 - content of coaching
 - ease of use
 - timing of calls
 - * reminder calls
 - timing of calls
 - * logbooks
 - * instruction books
6. Tell me about your home exercise
 - * what contributed to your ability
 - * what did you have to overcome or tell me about why the exercise was not done at home.
7. Have you noticed any changes over the last 2 years?
 - * how you feel
 - * what you do on a daily basis
 - * how you move
 - * how you think of movement
8. Have you noticed any changes in your beliefs during the course of this study?
9. How might things have been different if you did not take part in the BOOST study?
10. If you were in the position in telling persons with arthritis, who know the value of exercise but do not exercise, what would you recommend?
 - * what do you think will help them?

11. Are there any other technologies, or approaches you think would help people continue with their exercise program? Particularly when formal classes/instructions are completed?

APPENDIX B

Excerpt of chart for comparing focus codes among participants with high versus low adherence to exercise

| Pseudo Name | C or I | Adherence | Fits into life | Monitoring | Pacing | Professional instruction | Competition | Partners | Dedicated space |
|-------------|--------|-----------|-------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------|
| Jenny | C | H (10) | going for a walk, stop and do exercises | 1. even if it is a recording, check in, somebody's really concerned your doing the exercises 2. have more space to write in log book to explain why not being able to do exercises "so you would have known" | felt she was working according to her needs, go up with weights when she felt comfortable enough | 1. Somebody supervising the movement, she knew exactly the expectation to get it done correctly for safety's sake 2. made a big difference to go home and be sure exactly how to do them 3. As a result of being watched closely, she "just felt that I knew what I was doing". | | | Bedroom was her best place |
| Rebecca | I | H (10) | | Calls showed the Boost Program cared about you, make sure doing exercise, following protocol 2. send email or note to keep the connection | People worked at their own pace in the group | Loved coming to classes, the instructors went through everything, she was able to overcome the challenges, "I have to do this" | | | Bedroom |
| Dee | C | H (7) | find the fit to work into daily life | 1. find others with suffering, for same type of process, "yeah that happens to me too" and learn some have more issues 2. use email for reminders | 1. Increase as she could, do a "little bit more," everyone worked at their own pace 2. one step at a time, get a routine 3. If it gets "real painful" she can stop 4. don't get rushed into anything 5. if weights feel "too much" can go down on the weights, exercise was flexible and that was good | | 1. Some participants had more issues in common than others. 2. She learned of different "types of things affect people" of which some she had in common, "Yeah, that happens to me too" | | Livingroom because it had more space, could move the table out of the way |
| Lyndsey | C | H (8.5) | take the stair instead of the escalator | Enough to help people, give a reminder to exercise | If she didn't feel up to exercising, "do one today, tomorrow try two" | | | | |
| Audrey | C | L (0) | | 1. use of fit bit, challenge yourself with others is motivating 2. would have liked a "check-in", how you doing, what are problems | don't set great big goals, start with 10 minutes, next week do 15. It means something "you have to start somewhere" | 1. A physical therapist can help motivate, help get you started with exercises. 2. she valued the individual exercises she was given, different from others in the group due to a "particular problem" with her knee | Finds getting message from fitbit, "Great Job... you walked further than anybody in your age group today" as very motivating to "go a little bit further" | She would recommend finding a buddy, closer to your age to provide accountability. Reciprocal encouragement and motivator. Would settle for a phone call "How you doing? What are the problems, what are the issues" | |
| Francis | C | L (0) | | 1. Felt she was older and behind others in the group, yet saw another person slower than her, and learned and felt comfortable 2. at hotel gym, compared herself to others "going like mad" when she would sit on bike and go slow 3. would have liked personal contact as follow up, "why you weren't doing it" | | | | Buddy would make a difference, provide her with sense of commitment to that person and hence get more committed to exercise. | |
| Jake | C | L (0) | kept doing the exercises he felt was doing the most for him | Easy to do things when asked in person and see others doing it | | | | He would call a friend when he realized he was not exercising often enough on | |
| Carlotta | C | L (1) | | Could see where she was, opposed to where others were, and how they were coming along. See other's doing better gave her incentive 2. have reunion every now and again, see who is having difficulties and how you can change that | | | After noticing others doing better, she felt "incentive to keep on with what you have to do" | | |

APPENDIX C

Sensitivity analysis Study #2

Table 1. Descriptive data on 3 subjects who did not complete sit-stand x 10 at baseline

| ID | Age | BMI | Sit-to-stand (STS) x5 | Pain with STS | WOMAC Function | WOMAC Pain | TUG | Stair | TSK |
|------|-----|-----|-----------------------|---------------|----------------|------------|------|-------|-----|
| 53 | 59 | 26 | 13.53 | Yes | 11 | 8 | 5.72 | 9.82 | 35 |
| 56 | 56 | 33 | 25.53 | Yes | 40 | 13 | 13.6 | 45.3 | 41 |
| 69 | 58 | 28 | 24.15 | Yes | 50 | 11 | 10.4 | 15.7 | 39 |
| BLM* | 63 | 31 | 15.2 | n/a | 21 | 7 | 8.0 | 16.1 | 32 |

* Baseline mean of all subjects

Table 2. Imputed values for above 3 subjects into the sit-to-stand x 10 simple regression model of whole population. Test: $y=a+BX$

| | |
|-------|---------------------------------|
| ID 53 | $y=1.8+1.88(13.53)$ $y=27.2$ |
| ID 56 | $y=1.8+1.88(25.53)$ $y=49.8$ |
| ID 69 | $y=1.8+1.88(24.15)$ $y=47.2$ |

Table 3. Effect size comparisons for change in kinesiophobia

| | |
|---------------------------------|------|
| Fitzgerald et al. ⁷⁸ | 0.19 |
| Study #2 | 0.10 |

Table 4. Baseline TSK scores from other studies

| TSK Format | Mean (SD) | Condition |
|------------|-----------|------------------------------------------------|
| 17 item | 42 (7.7) | Chronic low back pain ²⁶ |
| 17 item | 28 (7.1) | Fibromyalgia ⁸³ |
| 17 item | 34 (6.2) | Obesity with knee osteoarthritis ³⁰ |
| 11 item | 21 (5.3) | ≤ 90 days post knee surgery ⁸¹ |
| 11 item | 14 (4.0) | Knee osteoarthritis ²⁸ |
| 6 item | 13 (3.7) | Knee and hip osteoarthritis ²⁹ |

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